Is phalloplasty (with urethral lengthening) surgery right for you?

Introduction:

This guide will help you decide if phalloplasty as a technique for masculinising gender affirmation (genital) surgery, is right for you. It explains what phalloplasty is, how these surgeries are done, what the risks and side effects are, and what you need to do to prepare and recover well from surgery. Please remember the information provided here does not replace the information you receive from your surgeon which will be tailored to your individual needs. We are constantly working to improve our resources to better suit your needs, this resource will continue to be updated.

Acknowledgements:

The primary sources of information in this decision booklet have been derived from the OSHU and Trans Care BC patient information.

What is phalloplasty surgery?

Phalloplasty is a series of complex reconstructive procedures, involving multiple steps and a series of four staged surgeries over two years to create a phallus with tissue from elsewhere on the body. A large part of its success depends on your preparedness. This means being in the best possible physical and mental health before the surgery. Above all else, it is critical to have reasonable expectations about what is possible for your body and what your surgeon can realistically accomplish. Our plastic surgeon and reconstructive urologist do various stages of this surgery. Phalloplasty can be done in many ways.

A phalloplasty may include some or all of these procedures:

- Creation of a shaft
- Creation of a urethra within the shaft (urethral lengthening)
- Creation of a segment of urethra, called a perineal urethra, to connect the existing urethra to the shaft urethra
- Scrotoplasty (creation of a scrotum)
- Vaginectomy (removal of the vagina)
- Burial of clitoral tissue
- Glansplasty (creation of a circumcised-appearing tip)

- Erectile device implant (inflatable or semi-rigid)
- Testicular implants

Phalloplasty, in ideal circumstances, can enable people to:

- Have a body that more closely aligns with their gender.
- Have a phallus with sensation.
- Have intercourse with an external or internal device.
- Urinate while standing (only possible with urethral lengthening).
- Each patient's surgery and results are different due to varying factors including age, weight, skin quality and elasticity and their overall health.

What is the preparation needed for phalloplasty surgery?

- If you are eligible for surgery, you will have your appointments and surgery in Wellington.
- Any person undergoing phalloplasty must have realistic expectations of what can be achieved through surgery and can collaborate with the treatment team.
- Due to the nature of this surgery people will need to have been taking testosterone as part of their gender affirming healthcare for a minimum of one year.
- You need to be able to tolerate a general anesthetic and lay on an operating table for up to eight hours.

WPATH eligibility for gender affirming (genital) surgery (GAgS):

To be eligible for GAgS you must meet the following criteria from WPATH Standards of Care (Version seven):

- Persistent, well-documented gender dysphoria
- Undergone a physical and psychological assessment by qualified gender specialists
- Demonstrate that you have been living as your chosen gender for at least one year prior to surgery
- Capacity to make a fully informed decision and to consent for treatment

- Age of consent in the given country. In Aotearoa New Zealand, you need to be aged 18 or over
- If significant medical or mental health concerns are present, they must be well controlled

Weight:

Being overweight is a risk factor for complications and delayed healing. The GAgS service accepts people with a BMI less than 35 on to the wait list. You will be supported to reduce and maintain your weight at a BMI of less than 30 to decrease general surgery risk. Weight also affects tissue thickness which may mean a certain type of flap phalloplasty is not possible such as thigh flap (ALT).

Smoking and vaping:

Smoking and nicotine-based vaping, interferes with the healing process and you are required to be a non-smoker (including nicotine-based vapes) to be eligible for phalloplasty. Nicotine can cause complications, including poor wound healing, delayed wound healing and increases the risk of graft failure. Research shows that the risk of surgery failure increases ten times for people who smoke even one cigarette a day. All products that contain nicotine including vapes and gum, although healthier alternatives to smoking tobacco, all still have the same negative effect on wound healing. (Source: OSHU Transgender Health Program and Department for Urology).

You are encouraged to speak with your GP regarding nicotine cessation support as people need to be a minimum of twelve weeks nicotine free.

Smoking cannabis, just as for smoking tobacco, contributes to the deterioration of your respiratory system and may interfere with your postoperative recovery.

What to consider:

We encourage you to:

- Consider your surgical goal and priorities and balance these with the risks.
- Vaginectomy is required for urethral lengthening. You will need to have had a hysterectomy prior to phalloplasty.

- If keeping your vaginal canal or reproductive organs is important to you, we urge you to consider shaft only phalloplasty without a new penile urethra.
- Your mental health and psychosocial supports. Having good mental health and psychosocial support is crucial for optimal healing.

Mental health and psychological / social support:

Gender affirmation surgeries generate multiple changes in the life of the patient. To successfully adapt to all these changes, it may be necessary to seek the help of healthcare professionals in addition to that of your friends, loved ones or support people. Please keep in mind that each person's surgical plan and experience are unique. It is recommended you engage with a counsellor or therapist before surgery, to develop strategies to prepare and respond to the challenges of phalloplasty surgery and to help navigate this challenging and exciting period of your life.

Phalloplasty options:

It is helpful to consider that deciding on a phalloplasty involves two components:

- Where to take the tissue from (donor site).
- Staging of the surgery

Keep that framework in mind as you read through the next few sections of this booklet.

What are the various types of phalloplasty?

Tube-within-a-tube phalloplasty:

We use one piece of tissue to form two tubes. One has skin on the outside for a shaft, and one has skin on the inside for the urethra. The tissue usually comes from the forearm. In very thin patients, it can come from the thigh, but the most common type is the radial forearm free flap (RFF), from where we take the skin, blood vessels and nerves to construct the phallus.

Shaft phalloplasty:

Only an outer tube is created, and the patient continues to urinate from their existing urethra. Patients can still choose to have the vaginal lining removed;

creation of a scrotum; and burial of the clitoris. Or they can have a scrotum created while keeping the vaginal canal. All donor sites (where tissue is taken from) are options.

Composite phalloplasty:

This is an option for patients who aren't good candidates for a tube-within-a-tube phalloplasty. The surgeon uses two pieces of tissue, usually from the thigh and forearm, to create the shaft and urethra separately.

What is a donor site?

This means we take tissue from another part or parts of your body (donor site) to construct a phallus and require often the second reconstruction procedure described below to the imperfection that results.

Reconstruction of the donor site:

After we remove donor tissue from your thigh or forearm, we cover it with a skin graft to help it heal. We use a fine shaver to take a thin layer of tissue, called a split-thickness skin graft, from your thigh. We then attach it to the donor site wound, and it heals like a layer of skin. The shaved area on your thigh will look and heal like a large road rash.

Healing time of the donor site:

- One week for graft to stick to wound.
- Ten days until you can get your skin graft wet.
- Three to five weeks for it to be Fully healed. Physical therapy can start at ten days after skin graft to the arm, and after four weeks for the thigh.

As every person heals differently, your surgeon will tell you if you can start any of your usual activities at your post operative appointments.

Factors to consider if you choose phalloplasty with urethral lengthening:

- You may experience a higher risk of complications, such as fistula, stricture, or urinary tract infection.

- We do not currently have good scientific studies that explore the long-term risks of creating a urethra. It is important to consider that unforeseen long-term issues could require ongoing medical or surgical care in the future.
- You can choose between the forearm and thigh donor sites. (Thigh is only possible if the patient is very thin/ has a low BMI within the healthy range.)
- Composite flaps are used in rare circumstances because the surgical risk with composites is elevated. Erectile implants are harder to place, and urinary spray is more frequent with composite flaps.
- You will be required to get a hysterectomy prior to phalloplasty.

Phallus length:

It is impossible to predict the exact length of your phallus. We can give you a general estimate after doing an exam during consultation. Your phallus will probably get longer throughout your life because skin stretches as you get older. One factor affecting phallic length that is not within our control is the amount of skin elasticity.

Hair removal (essential with urethral lengthening):

You will need electrolysis or laser treatment to permanently remove hair on the donor site (forearm and/or thigh) used to make the urethra. Hair remaining within the urethra can lead to significant urologic complications, such as urethral stones and recurrent infections. Skin has lots of hair follicles and this hair needs to be removed before the skin is transferred to construct a urethra. Electrolysis and / or laser hair removal is needed to provide hair-free tissue for this procedure. For adequate hair removal to occur the process can take over nine months.
Many people also want to remove hair from the outside of the phallus, but it's not required. This can be done before or after your first surgery. Your surgeon will determine whether and where you need hair removal.

What are the various stages of phalloplasty surgery?

Stages and timeline:

Phalloplasty can include a combination of several surgeries. You can choose some or all of these procedures. Each patient's process is different. Your surgeon will talk with you about the best options for you. For people for whom standing to urinate is important and have chosen phalloplasty with urethral lengthening, we offer the tube within a tube and composite flaps for phallic creation with a urethra. This surgery is performed in four stages.

Phalloplasty surgery sequence:

Phalloplasty typically requires four stages over two years, though there are many variations. You must wait at least four to six months between each step. This is the minimal delay that is applicable for healing process without any complications. In case of complications or if there is any delay in healing including fistula the wait time will be longer. Your surgeon will discuss options with you.

First surgery stage:

The plastic surgeon introduces new tissues from the donor site and attaches these to construct the new phallus. You will still urinate sitting down following this stage from your original urethral site. It is very important to follow all your surgeons' instructions following stage one to minimise flap failure, including bed rest and constant monitoring.

Second surgery stage, about six months later:

Depending on choices, either the plastic surgeon or urologist:

- Removes the vagina and introduces another flap to fill this space (gracilus muscle)
- Connects the urethra
- Creates a scrotum
- Forms a circumcised appearance (glansplasty)
- Places two temporary catheters (thin tubes), one through the phallus and one through the abdomen.
- It is crucial to follow all your surgeons' instructions following the second stage of surgery, it is following this stage that most urinary issues present.

Third surgery stage, about six to nine months later (if a patient chooses these option):

- Testicular implants placed

Fourth Surgery stage, about nine to twelve months later (if a patient chooses this option):

- Erectile device implanted

What complications may arise during surgery?

It is important that you understand that there are possible risks linked with any major operation such as phalloplasty. All surgical procedures involve some risks, including negative reactions to anaesthesia, blood loss, blood clots and infection. These complications can, in extreme cases, result in death. It's important to discuss these risks in detail with your surgeon.

What happens after the operation?

- When you wake up after surgery you will feel tired, and your energy level will be decreased. You will be kept in a recovery area, where specialised staff will take care of you until you are fit to return to your hospital room. Pain medication will be administered to alleviate you having any discomfort before you wake up. You will spend five days in hospital recovering before being discharged.
- A urinary catheter will be in place after surgery, to allow you to pass urine while your urethra heals and to allow staff to accurately monitor your urine output. The catheter will have been inserted while you are under general anaesthetic.
- It takes between eight to twelve (possibly more) weeks to recover from each stage of phalloplasty surgery, depending on which type is carried out. You should expect to take at least six weeks off work and avoid heavy lifting and exercise during the recovery period.
- The surgeon will see you two weeks after surgery, to approve your travel to your home area.
- Partial funding is available to arrange accommodation near the hospital if your home is out of Wellington.

Physical restrictions after surgery:

After your first and second stage of surgery you are encouraged to avoid any strenuous activity. Once you are released from hospital after these stages, anticipate restricted physical activity for up to a further six weeks. We recommend

finding ways to function within these physical limits before surgery, while you are feeling well.

Post-surgery complications are a possibility, but these will be managed closely by the surgeon and the GAgSS service. Although most urethral complications occur in the immediate and intermediate postoperative period, following stage two, complications can occur at any time over your lifetime.

What are the side effects of surgery (which will happen?)

Bruising and swelling:

Moderate pain and swelling are expected for up to seven days after your surgery, and pain medication will be prescribed for you. Swelling may be worse after sitting or standing for a long time.

Scarring:

Scars will occur as part of the surgery. The surgeon will try to minimise the scars and place them where possible in natural folds, so they are not so visible. You will be advised how to care for your scars as they heal, for up to one year after surgery.

Altered sensation/numbness:

- It can take time to heal, recover, and adjust to sex and intimacy after gender-affirming surgery.
- It may take a while to get used to your new body, so although you can participate in and enjoy sexual activity from six weeks post-surgery, it is also perfectly natural to want to take things slowly.
- You may experience a shooting or tingling sensation as the nerves regrow, which can take three to six months to return to normal, and sometimes for as long as a year.

Pain:

Pain following surgery is inevitable, and everyone's experience is unique. Patients feel different levels and types of pain for varying lengths of time. Patients may report pain at some surgical areas and none at others. While most pain subsides over the first four to six weeks following each stage, minor discomfort or pain is normal even beyond the normal healing period. It usually subsides within a year after surgery.

While uncommon, it is possible for patients to have long-term chronic pain. Persistent pain — especially a burning or shocking type of pain — can be caused by types of nerve pain at the surgical site. This pain can occur both at the donor sites (thigh and/or forearm) as well as the groin. If you have persistent pain, let your surgical team know. There are both therapy and surgical options available to manage these complications.

Post operative expectations:

Complications:

Our goal is to prevent complications. We do this by using careful surgical techniques, completing the phalloplasty in multiple stages, helping you to be in the best health, and ensuring that you have a safe plan for your recovery. However, this is a very complex surgery, and complications are common. We recommend that you prepare yourself — both emotionally and practically — for the possibility of complications. Our team is here to help you with anything that may arise. We do everything we can to ensure your surgery and recovery are as smooth as possible.

Infection:

Infection is a frequent and common risk to many surgeries. An infection occurs when tissues are affected by microorganisms such as bacteria and/or other pathogens. An infection can be treated with antibiotic ointment or with antibiotics taken orally or intravenously.

Infection is possible at the phalloplasty site as well as the flap and skin graft donor sites. Signs of infection generally include spreading redness, pus discharge, odour, swelling, warmth to touch, red streaking, or fever. If you are concerned about a possible infection, contact our office immediately and your GP or local hospital.

Hematoma:

Hematoma is a collection of blood. Surgical site hematomas occur from a blood vessel that is actively bleeding following a surgery. Small hematomas typically heal on their own. Large hematomas may need to be drained or the patient may need to return to the operating room to stop the blood vessel from bleeding, however this is rare. Hematomas are most likely to occur within the first few days following surgery. Remember, you will have a lot of swelling at the surgical site. This is normal.

Granulation tissue:

This is an area of bright red or pink tissue around an incision where healing is not complete. It can sometimes show up as painless bleeding or spotting. It is quite common and can be easily treated during follow up appointments.

Graft failure:

Sometimes a skin graft is used from your inner cheek to help strengthen your urethra. Total failure of the graft is rare. It is more common for small areas to fail. These typically resolve on their own or with nonsurgical intervention. Graft failure may also result in urethral fistula or stricture, discussed further down.

Wound separation, reopening of wounds and/or slow healing:

This is one of the more common complications after surgery. The healing process is influenced by a series of factors: oedema, infection, strain on wounds, deficient blood circulation, alcohol use, smoking, poor nutrition, etc. These factors can slow healing and cause the reopening of wounds that require a longer healing period. Generally, this does not affect the final appearance of the operated area. Wound separation occurs when two areas of skin have been stitched together, but the skin edges pull apart after surgery. This typically heals on its own if the suite is kept clean and dry. This is one of the more common complications after surgery.

Flap loss:

Flap loss can occur when all or part of the flap dies due to poor blood flow. Total flap loss is rare but is a risk that patients should know about. If part of the flap dies, the affected portion can be removed by your surgeon, and the phallus can be reconstructed immediately or at a later date. Therefore, proper phallus position and body position are vital during this time to ensure the best possible blood flow to the phallus.

Skin graft loss:

The flap donor site (forearm and/or thigh) is covered with a thin layer of skin taken from the thigh (opposite thigh if using a thigh-based flap). This skin will survive by adhering and getting oxygen from the wound bed underneath. If the graft does not attach, then some areas may not survive and will need to be removed. Small areas will fill in as the wound heals. If a large area is lost, a repeat skin graft may be needed to cover the region.

Loss of sensation and pain hypersensitivity:

Nerves are removed from the forearm and connected to nerves in the genital area to maintain sensation. The clitoris is preserved and buried at the base of the phallus to maintain orgasmic capacity. It is possible that some of the reconnection of the nerves may fail and that partial or total loss of sensation and/or numbness may result.

Following surgery, you may experience numbness due to swelling and stretching of the tissues. It is possible that part of the genital area will not regain sensitivity or, on the contrary, that some areas will remain hypersensitive and painful. This can affect the sexual response and alter the ability to experience pleasure. This situation should return to normal after a few months. However, numbness in some areas may persist and the sensation may not return completely.

Enlarged and thick scars (keloid):

The scarring process differs from person to person and scars may become larger and/or thicker on the arm, thigh, phallus, or genital area. Your own scarring history should be a good indication of what you can expect. If your scars are large and/or thick, they can sometimes be corrected with medications such as steroid injections and silicone dressings.

Skin graft and coloration of the donor site, radial forearm free-flap (RFF) technique:

In the first stage of RFF, a skin flap of full thickness is taken from the forearm until the muscles and tendons are exposed, for the construction of the phallus. A thin layer of skin from the thigh is used to cover the loss of forearm tissue. It is possible during the scarring process that part of the graft or the entire graft may not adhere to the donor arm, leading to partial or complete exposure of the muscles or tendons. This requires immediate special medical attention. Healing of the skin contour of the forearm may be irregular and very slow in some people. Abnormal and/or excessive scarring may also occur making the appearance of the forearm less aesthetic. Some treatments or surgery are sometimes possible to improve the appearance of the healing. The surgical site of the thigh may show intense redness at the beginning of the healing process and then, over time, take on a paler colour. The redness of the scars will diminish when you resume your activities and may take up to a year to fade, but it can also remain permanently. The colour of the forearm surgery site may also be affected by changes in temperature (cold or hot).

Graft site sensitivity:

Itching may become chronic in the thigh or arm and skin sensitivity may be temporarily or permanently diminished. The skin graft may not restore the normal functions of intact skin. Grafted skin is more fragile than normal skin. Very rarely, chronic pain may develop because of skin grafting.

Non-compliance with post operative instructions:

It is very important that the forearm skin graft is not subjected to excessive force, swelling, abrasion, or improper movement until it has healed completely. The consequence could be the loss of the graft. Personal and professional activities must be adjusted accordingly.

Mucocele/vaginal remnant:

If you have a vaginectomy, rarely vaginal tissue can be left behind, and you may develop a collection of fluid and cells in your pelvis. Sometimes this connects to your urethra. This is usually diagnosed by radiographic exams and may require a second surgery to remove that tissue.

Partial or total loss of phallus related to ischemia following stage one:

Phallus grafting to the genital area requires the connection of multiple small blood vessels and nerves and is very fragile, especially in the first few days after surgery and requires specialized care. Ischemia is a lack of blood flow that leads to tissue death (necrosis) due to lack of oxygen. A clot can form inside a blood vessel in the phallus and block the blood supply to part of the phallus. This complication requires immediate surgery to remove the clot and can lead to necrosis. Necrosis occurs when the blood supply to a tissue is cut off or obstructed for a period. Tissues with no blood supply do not survive and this can lead to partial or total loss of the phallus. If the tissue has suffered from a lack of blood supply, it is possible that part of the phallus may become detached, and the rest of the healthy tissue will continue its healing process. Although very rare, if the blood flow has stopped completely inside the phallus for a long time, it is possible that the phallus may not survive, and total loss of the phallus may result.

Recto-vaginal fistula, perineal sinus, and peritonitis:

A fistula is an abnormal connection between two spaces. It can occur following a phalloplasty and result in abnormal connection between the old vaginal cavity and the rectum. Surgery is then required to close the fistula. A perineal sinus is a small

path or pocket that forms after the vaginal cavity is closed where fluid can accumulate. Surgery is required to remove it. Peritonitis can be caused by a perforation from the vaginal cul-de-sac to the peritoneal cavity that is undetected during surgery or in the following days. Surgery will be essential.

Persistent edema or poor circulation in the hand (RFF):

Because of the harvesting of large vessels from the donor forearm, swelling may persist in the donor arm hand or circulation may be disrupted, leading to cold intolerance, stiffness, or a feeling of a stiff hand. There may also be a decrease in hand strength.

Urinary complications following stage two / long term:

Genital surgery can lead to complications in the urinary tract. A urinary catheter is required for a minimum of three weeks following stage two of surgery. The bladder may produce spasms in response to the catheter that can cause urine leakage. Normally, the spasms stop when the catheter is removed.

Signs and symptoms of urinary tract infections should also be monitored. When the urinary catheter is removed, the urinary stream may be irregular and off-center due to changes in the anatomy of the urethra. Difficulty controlling your urge to urinate, and involuntary leakage of urine may occur following surgery. The causes are different from person to person and should be discussed with your doctor. A fistula, stenosis, or diverticulum may also form in the portion of the urethra that was lengthened during surgery.

It is estimated that 70% of urinary complications occur following stage two for those who receive urethral lengthening. Long term you will need ongoing urology follow up.

Urinary fistula:

During the healing process, it is possible for small openings in the urethra to appear, from which urine can leak. If your surgery involves lengthening of your urethra, fistulas most commonly form at the junction of the native and new urethra. They can also happen anywhere along the new urethral tube. Catheters are usually placed to divert urine way from the opening for several weeks, allowing for it to heal. Fistulas may close on their own over time. However, if no improvement is evident after 6 months, your surgeon may need to perform another surgery to close them.

Urethral stricture:

Urethral stricture is the narrowing of the internal circumference of the urethra (which passes urine). It can occur at any time during the healing process. Signs of urethral stricture can include:

- Decreased force of your urinary stream and slow urinary flow.
- The time it takes for the bladder to empty increases.
- The sensation of the bladder not being emptied completely.
- Frequent urge to urinate.
- Extra effort is necessary to urinate.
- Difficulty urinating.

Recurrent urinary infections can be a sign of a stricture.

Fixing a stricture may involve further additional surgery.

Urine stream irregularity

You may have trouble urinating while standing up after urethral surgery. Sometimes inflammation and swelling can cause urine to spray or your stream to be unpredictable. The problem may be temporary or permanent. Your surgeon will do all they can to fix it.

Urinary spray:

If you have a new urethra, you may experience an irregular urinary stream or spray, making it challenging to stand during urination. Urinary spray can improve over several months as the surgical sites heal, but it can also be an ongoing issue. Your surgeon may be able to address this issue by adjusting the urethral opening.

Post-void dribble:

If you have a new penile urethra, it is very common to experience post-void dribble. Everyone who has urethral reconstructive surgery experiences this post-void dribbling. This happens when a small amount of urine remains in the new urethra following urination and this excess urine dribbles from the phallus. It is a difficult issue to treat surgically; however, the patient can help remove the retained urine by gently pressing along the outside of the urethra (milking). It may improve with time, or it may not.

Diverticulum:

A diverticulum is a cavity in the shape of a small "pouch" that can form in part of the urethral wall where urine can collect. Surgery is often needed to remove the diverticulum. A diverticulum may also form in the old vaginal cavity, which also requires surgery to remove it.

Narrow urethral opening:

The meatus (urethral opening) can narrow and may cause urinary spray. Usually, meatal revisions can be done in the clinic without need for a urinary catheter.

Hair regrowth in the urethra:

Hairiness is influenced by various factors including skin colour and hormones. To avoid complications, permanent hair removal from the part of the arm that will be used for the construction of the inside of the urethra is mandatory. Despite permanent hair removal, it is possible that hair may grow back inside the urethra after a certain amount of time. This can cause urinary problems.

Implants (the erectile device and/or testicular implants) have potential for several complications:

They are foreign objects in the body and therefore have the potential to become infected. It is also possible for them to become dislodged from the attachment to the bone, for their parts to malfunction and/or fail and no longer work, or for the erectile device to push through the skin over time. (This is called extrusion.)

Some patients also experience chronic or situational pain from the implants (both testicular and erectile device), such as during intercourse or when riding a bike. Testicular implants can move to an undesirable location in the scrotum. Any of these complications could lead to implant removal and possible replacement.

Nerve injury and loss of sensation:

Following surgery there may be areas of numbness due to swelling and stretching of the tissue. You may have small areas of numbness that takes three to six months to return to normal. The perineal area may not regain sensitivity or, on the contrary, some areas may remain hypersensitive and painful. This can affect sexual response and alter the ability to experience pleasure. This situation should return to normal after a few months. However, numbness in some areas may persist and the sensation may not return completely. Should this occur, your ability to achieve orgasm could decrease. Loss of clitoris tissue is a remote possibility.

Perineal pit:

The area above the anus can form a small pit that can have hygiene implications. We may need to correct it with surgery.

You may benefit from a follow-up in physiotherapy for pelvic floor re-education.

Blood clots (sudden swelling in one leg or difficulty breathing):

Blood clots can form during and after surgery due to prolonged inactivity including being immobilized while under anesthetic. If you notice one of your legs swells suddenly or if you suddenly have a hard time breathing, you may have a blood clot, you should go to the emergency department straight away.

Please see our additional resources: **Choosing your Support Person** and the **Fact Sheet for Caregivers**